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Management of chronic disease by practitioners and patients: are we teaching the wrong things?

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The patient should be the primary manager of chronic disease, guided and coached by a doctor or other practitioner to devise the best therapeutic regimen.¹ The practitioner and patient should work as partners,² developing strategies that give the patient the best chance to control his or her own disease and reduce the physical, psychological, social, and economic consequences of chronic illness.

In this article we consider the quality of education for patients and practitioners who are trying to manage chronic disease. We argue that neither patients nor practitioners are taught the skills that will most enable each to carry out his or her role and responsibility for disease management. We use asthma, a chronic lung disease, to show how patients and practitioners are being taught the wrong things.

Methods

We searched Medline and used previously published reviews to find articles on managing asthma. We did not formally assess the methodological quality of individual studies.

Asthma: the knowledge gap

In recent decades there have been striking advances in the clinical treatment of asthma,² yet morbidity and

Summary points

Disease control, especially asthma, depends on the quality of partnership between patient and physician

Most current patient education activities are not adequately based on evaluated models of effective disease management

One such model, self regulation, has been shown to change patients' behaviour and improve their health status

Specific techniques can help doctors to develop partnerships with patients

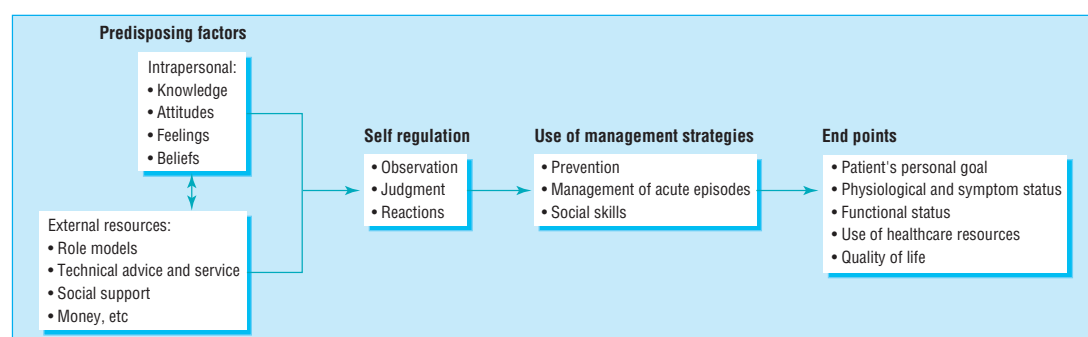
Including these techniques in doctors' education can lead to reduced use of and higher satisfaction with health care by patients with asthma

mortality for the disease are at an all time high.³ This gap between the scientific evidence and the continuing negative effect of asthma on society depends to a considerable extent on patients' behaviour and practition-

website
extra

Two tables listing
studies of asthma
patient education
appear on the
BMJ's website

www.bmj.com



Model of patient management of chronic lung disease (adapted with permission from Clark and Starr 1994¹²)

ers' performance.⁴ To understand what patients and clinicians must be taught to achieve disease control, we have to look first at the goals of treatment.

The goals of asthma treatment

The aim of treatment of asthma is to control symptoms, restore full physical and psychosocial functioning, and eliminate interference with social relationships and quality of life.² To reach these goals, people with asthma (including children and their parents) must at least be able to use prescribed drugs in the proper manner to prevent or control symptoms, identify and avoid the things that cause symptoms, develop or maintain family and other necessary social support, and communicate effectively with healthcare providers. Complicating this process is the fact that, apart from some very basic management strategies that are important for almost all people with asthma, the tasks of management are largely unique to each person. These tasks depend on individual disease characteristics, personal attributes, and aspects of lifestyle considerations, and on the way these change over time. Because asthma management is dynamic, people must develop their own repertoires of effective behavioural strategies and use a decision making process that allows them to change or refine strategies as needed.⁵ Furthermore, it is impossible for clinicians to provide direction for every contingency a patient may face, so individuals must exercise a high degree of independent decision making about asthma within their doctor's general guidelines.

These goals clearly reflect the need for full involvement of practitioner and patient in a partnership, a concept discussed extensively in the literature about disease management.⁶ But the dismal epidemiology of asthma suggests that neither partner is sufficiently effective in controlling the disease, and we think that inadequate preparation for this management role is an important factor in this.

Preparing the patient for effective disease management

The failure to adequately prepare patients for chronic disease management has two components: firstly, the failure to adopt and adapt existing education programmes of proved value⁷⁻⁸ and, secondly, the failure to see management by patients as a behavioural process based largely on an individual's ability to self regulate.⁹⁻¹⁰

Education programmes

Education for patients with asthma has become a routine part of many medical services. But most education provided, whether informal within consultations or formally organised into scheduled classes for groups of patients, is based on an ad hoc set of messages and skills that professionals believe patients need to acquire.¹¹ The relatively poor quality of most formal patient education on asthma, usually comprising didactic lectures from clinicians,¹¹ is surprising.

Since the mid-1980s several models of asthma education for children and adults, well designed and based on behavioural theory, have been evaluated and shown to achieve the desired outcomes, such as reduced use of health services and better quality of life. (Tables A and B on the *BMJ*'s website give details such model programmes.) These programmes are diverse and vary in format, teaching methods, and materials used. Each, however, is formulated from a theoretical understanding of human behaviour and recognises what predisposes patients to manage disease.

Self regulation

Theories of human behaviour based on accepted principles of learning and motivation can help us achieve the goal of optimum disease management. As an example, the figure shows a behavioural model based on three ideas.¹² The first idea is that several factors predispose or enable one to manage a disease. Secondly, management by the patient involves the conscious use of strategies to manipulate situations and thereby reduce the impact of disease on daily life. The patient learns what strategies work (or do not) through processes of self regulation. Thirdly, management is not an end in itself but is the means to other ends.

Self regulation is the process of observing, making judgments, and reacting realistically and appropriately to one's own efforts to manage a task. It is a means by which patients determine what they will do, given their specific goals, social context, and their perceptions of their own capability. For example, a young man with asthma who wants to play basketball thinks drugs will help and so uses them preventively, takes a reliever drug when exercising strenuously, seeks moral support from his friends and coaches, and uses other strategies that enable him to reach his personal goal. He learns which strategies are effective through self regulation.

Self regulation may be particularly important in diseases like asthma for which there is no proved formula for optimum management and patients and

Communication techniques derived from studies of the doctor-patient relationship

- 1 Attend to the patient (signalled by cues such as making eye contact, sitting rather than standing when conversing with the patient, moving closer to the patient, and leaning slightly forward to attend to the discussion)
- 2 Elicit the patient's underlying concerns about the condition
- 3 Construct reassuring messages that alleviate fears (reducing fear as a distraction enables the patient to focus on what you are saying)
- 4 Address any immediate concerns that the family expresses (enabling patients to refocus their attention toward the information being provided)
- 5 Engage the patient in interactive conversation through use of open ended questions, simple language, and analogies to teach important concepts (dialogue that is interactive produces richer information)
- 6 Tailor the treatment regimen by eliciting and addressing potential problems in the timing, dose, or side effects of the drugs recommended
- 7 Use appropriate non-verbal encouragement (such as a pat on the shoulder, nodding in agreement) and verbal praise when the patient reports using correct disease management strategies
- 8 Elicit the patient's immediate objective related to controlling the disease and reach agreement with the family on a short term goal (that is, a short term objective both provider and patient will strive to reach that is important to the patient)
- 9 Review the long term plan for the patient's treatment so the patient knows what to expect over time, knows the situations under which the physician will modify treatment, and knows the criteria for judging the success of the treatment plan
- 10 Help the patient plan in advance for decision making about the chronic condition (such as using diary information or guidelines for handling potential problems and exploring contingencies in managing the disease)

their families must exercise a high degree of decision making, usually in the absence of health professionals. Patients have to recognise when their disease impedes reaching their goals, judge what they might do to improve the situation, test management strategies by trying new behaviour; and draw conclusions. Patients also have to develop the confidence to carry out effective behaviour—that is, develop self efficacy.⁹

Thus effective patient education should not be a matter of simply providing information about the disease but should allow patients to develop the capacity to observe themselves, make sensible judgments, feel confident, and recognise desirable outcomes.¹³⁻¹⁶ There is little correlation between general knowledge about asthma and health outcomes.¹⁷ Similarly, the link between general attitudes and specific health behaviours is weak.¹⁸ Feeling able to carry out a management task makes people more likely to try the task,¹³⁻¹⁹ but confidence alone does not ensure suitable behaviour.

Defining success

What is the goal of patient education in asthma and what signals that the goal has been reached? Practitioners and patients bring different expertise to asthma control (technical versus experiential) and focus on different outcomes. The practitioner will often be concerned with the results of objective measures, such as pulmonary function tests, and the need for drugs. Patients focus more readily on their quality of life, such as the degree of disruption of normal activities. Measures assessing clinical outcome, functional health status, and quality of life do not always correlate well with each other.²⁰ A patient is much more likely to be motivated to follow a practitioner's

recommendations when the goal of management reflects the patient's own interests and concerns.

Preparing the practitioner for effective partnership with patients

While the general state of patient education in asthma falls far short of the standard set by evaluated models, the state of clinical education is even less robust. A review of postgraduate courses on asthma for doctors that are sponsored by professional associations, medical care facilities, pharmaceutical companies, and other providers, shows that they focus almost solely on therapeutic recommendations to doctors. The predominant topics are the correct choice and administration of drugs, the basic mechanisms of disease, the use of spirometry, and use of monitoring devices for patients (such as peak flow meters and symptom diaries). Furthermore, despite the wide availability of clinical education on asthma, research shows that in the United States doctors are not prescribing adequately²¹⁻²³ and that their patients are not following medical recommendations.¹⁻²⁴

Only a few empirical studies have examined the effect of education for practising doctors on the health of their patients²⁵⁻²⁷ or on patients' views about practitioners' performance.²⁸⁻²⁹

Communication and teaching skills for doctors

Many barriers to effective communication have been identified in studies of the doctor-patient relationship. Patients often feel that they are wasting the doctor's valuable time, omit details they deem unimportant, are embarrassed to mention things they think will place them in an unfavourable light, do not understand medical terms, and may believe the doctor has not really listened and therefore does not have the information needed to make a good treatment decision.³⁰ The box shows 10 proved techniques for improving communication and patient education.³¹

A large randomised controlled trial tested the inclusion of these communication principles in the education of paediatricians, evaluating the effects of this training on the doctors' behaviour and on the health status of their patients with asthma.³¹⁻³² The intervention was an interactive seminar comprising brief lectures from specialists, a videotape showing effective use of the 10 communication techniques, case studies presenting troublesome clinical problems, a protocol by which doctors could assess their own behaviour regarding communication with patients, and a review of messages to communicate and materials to use when teaching patients. The clinical content of the seminar was based on the guidelines of the US National Asthma Education Program Expert Panel.² At follow up about two years later, the doctors in the intervention group were more likely than those in the control group to write down for patients how to adjust drugs according to symptoms experienced and to provide guidelines for patients on how to adjust treatment when clinical conditions changed.³² Children seen by the doctors in the intervention group had fewer hospital admissions than the controls' patients, and their parents communicated more effectively with the doctors. Yet these doctors spent no more time with their asthma patients than did the control doctors, and

appropriate clinical treatment alone did not improve patients' health status.

Conclusions

Neither patients nor practitioners are being taught the right things about managing asthma. Relying on intuition, convenience, and habit (apparently the basis of most current education on asthma) will not do enough to enable patients and practitioners to control chronic disease. Effective teaching on chronic disease must be based more closely on the findings of behavioural research.

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A memorable patient Fascinating rhythm

A pianist in the Bill Evans style, he is a respected figure on the London jazz scene. His earliest icon was George Shearing, whom he heard as a teenager, but among his strongest influences were Horace Silver and Thelonius Monk. Like many of his idols, rhythm is what drives him, especially the challenging and the complex. It was this that made his medical history so intriguing.

In his late 30s, when his style and technique were beginning to mature, he developed a persistent pulsating noise in his left ear. A Harley Street surgeon diagnosed otosclerosis. At first he found the noise intrusive, but after a while his jazz and his tinnitus began to live in harmony. When he was playing, the sound of his jazz masked the noise in his ear; when he was resting, the noise in his ear provided a convenient backing for mental extemporisation. Apart from the odd missed beat, it kept perfect time.

Many years later, however, when his creative powers were at their peak, the pulsation became periodically irregular. Initially these episodes were short lived, but over time they increased both in frequency and duration and became a source of considerable distress. During attacks the tempo of the pulse quickened, its rhythm became chaotic, and he felt in a state of continuous alert. His confidence suffered, his mental improvisations ceased, and the quality of his playing began to decline.

Why the attacks affected him so profoundly is uncertain. In the course of his career he has experienced a wide variety of rhythms, ranging from the basic to the extraordinarily complex. Rhythmic patterns that perturb the uninitiated—crossrhythm, polymetre, etc—are second nature to him. Moreover, one of his favourite techniques is to play "outside the pulse," an aspect of the modern style in which, to use his words, "the pianist flirts with rhythmic disaster but never loses control." Did he find "rhythmic disaster" harder to cope with, having spent much of his life trying to avoid it?

Last year a physician diagnosed paroxysmal atrial fibrillation and prescribed sotalol and amiodarone. His rhythm section is now beating regularly, and some say they have never heard him playing so well.

David Cummins *clinical tutor, Harefield Hospital, Middlesex*

We welcome articles of up to 600 words on topics such as *A memorable patient*, *A paper that changed my practice*, *My most unfortunate mistake*, or any other piece conveying instruction, pathos, or humour. If possible the article should be supplied on a disk. Permission is needed from the patient or a relative if an identifiable patient is referred to.